<BillNo> <Sponsor>

HOUSE JOINT RESOLUTION 201

By Helton

A RESOLUTION to honor the efforts to raise awareness of Alexander disease in Tennessee.

WHEREAS, Alexander disease is a very rare autosomal dominant leukodystrophy, which are neurological conditions caused by anomalies in the myelin that protects nerve fibers in the brain; and

WHEREAS, since the disease was first described in 1949, approximately 500 cases have been reported, with four patients currently living in Tennessee, Grayson Berry Ledbetter of Chattanooga, John Cameron Copeland of Chattanooga, Meris Brynn White of Knoxville, and Gregory Chayse Andrews of Hampton; and

WHEREAS, while there is no treatment or cure for Alexander disease, there is hope, as promising results in medical tests since 2016 have paved the path toward clinical trials of a drug to treat Alexander disease that will begin in 2021; and

WHEREAS, efforts to raise awareness of this rare disease and its impact on those afflicted and their families are underway; and

WHEREAS, in 2019, End Alexander Disease was established with a mission to be a catalyst for research and development of a treatment, and eventual cure, of Alexander disease and to help those with this disease and other types of leukodystrophy get the care they need; and

WHEREAS, End Alexander Disease is also working to raise funds to assist those with Alexander disease and raise awareness of this ultra-rare disease; now, therefore,

BE IT RESOLVED BY THE HOUSE OF REPRESENTATIVES OF THE ONE HUNDRED TWELFTH GENERAL ASSEMBLY OF THE STATE OF TENNESSEE, THE SENATE

CONCURRING, that we honor and commend End Alexander Disease and its efforts to raise awareness of Alexander disease in Tennessee.

BE IT FURTHER RESOLVED, that an appropriate copy of this resolution be prepared for presentation with this final clause omitted from such copy and upon proper request made to the appropriate clerk, the language appearing immediately following the State seal appear without House or Senate designation.